

Financing Developing Newborn Screening Systems

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PEDIATRICS[®]

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A Look at Newborn Screening: Today and Tomorrow
Pediatrics 2006;117:5.

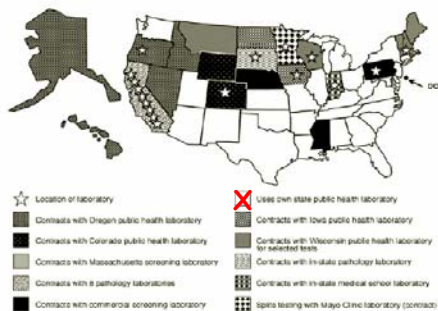
This information is current as of October 17, 2006

Status of Newborn Screening Programs in the United States

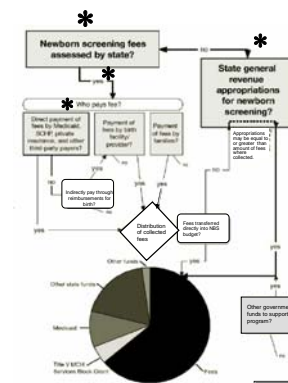
Bradford L. Therrell, Alissa Johnson, and Donna Williams
Pediatrics 2006;117:212-252

Financing State Newborn Screening Programs: Sources and Uses of Funds

Kay Johnson, Michele A. Lloyd-Puryear, Marie Y. Mann, Lauren Raskin Ramos, and Bradford L. Therrell
Pediatrics 2006;117:270-279



Pediatrics 2006;117:212-252



Pediatrics 2006;117:270-279

Results: Fee Labs

- 73% increased fees 2002 – 2005
- 100% use funds to support laboratory
- 70% use funds for short term FU services
- 47% finance long-term FU beyond diagnosis
- 43% finance genetic or nutritional counseling and foods or treatments

Pediatrics 2006;117:270-279

State	2002	2003	2004	2005	2006	2007	2008
Alabama	\$0	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Alaska	\$0	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
Arizona	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Arkansas	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
California	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Colorado	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Connecticut	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Delaware	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
District of Columbia	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Florida	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Georgia	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Hawaii	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Idaho	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Illinois	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Indiana	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Iowa	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Kansas	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Kentucky	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Louisiana	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Maine	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Maryland	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Massachusetts	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Michigan	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Minnesota	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Mississippi	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Missouri	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Montana	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Nebraska	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Nevada	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
New Hampshire	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
New Jersey	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
New Mexico	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
New York	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
North Carolina	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
North Dakota	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Ohio	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Oklahoma	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Oregon	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Pennsylvania	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Rhode Island	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
South Carolina	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
South Dakota	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Tennessee	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Texas	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Utah	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Vermont	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Virginia	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Washington	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
West Virginia	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Wisconsin	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00
Wyoming	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00	\$10.00

No Fee

DC
Georgia
Iowa
New Mexico
New York
West Virginia

Highest fee: \$139.99

Lowest fee: \$14.50

Pediatrics 2006;117:270-279

Conclusions

- States are committed to maintaining their NBS programs
- States are committed to financing the initial screening and diagnosis
- Use of Federal funding is limited
- Federal funding could (would?) increase with national guidelines

Pediatrics 2006;117:270-279

APHL

Recommendations from the American College of Medical Genetics for a uniform newborn screening core panel of 29 conditions require rapid expansion of state public health newborn screening programs and laboratories. **APHL supports continued federal and state funding** to enable programs to comply with these recommendations. Furthermore, to assure continued compliance with evolving recommendations, **resources generated by, or allocated to, a newborn screening system should be dedicated to that system, and should cover all phases of system operations (laboratory screening, follow-up, therapy, and education) including new assay and system development.**

APHL Position Paper not yet
officially adopted, Oct 2006